



# The framework for the management of bleeding disorders in Australia

National Blood Authority

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National Blood Authority  
Level 2 243 Northbourne Avenue  
Lyneham ACT 2602  
Telephone: +61 2 6151 5000  
Email: [support@blood.gov.au](mailto:support@blood.gov.au)  
Website: [www.blood.gov.au](http://www.blood.gov.au)

#### **Disclaimer**

This document provides an overview of the governance structures in Australia to allow people with bleeding disorders access to appropriate care and treatment. It is not a guide to appropriate practice and should be read in conjunction with the Australian Haemophilia Centre Director's Organisation's position statement to the 2020 World Federation Guidelines for the Management of Hemophilia. The information within is subject to change over time.

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## 1. Introduction

Bleeding disorders are medical conditions where the body's ability to control bleeding is impaired. These disorders can lead to excessive bleeding from injuries, spontaneous bleeding, or difficulty stopping bleeding after surgery.

Common types of bleeding disorders include:

- haemophilia A – deficiency in coagulation factor VIII
- haemophilia B – deficiency in coagulation factor IX
- von Willebrand disease – deficiency in von Willebrand factor.

There are several other rarer bleeding disorders including rare clotting factor deficiencies, inherited platelet disorders and acquired haemophilia.

The best outcomes for patients with bleeding disorders are achieved through a comprehensive care model, within which members of a dedicated team manage not only the direct bleeding complications of bleeding disorders but also other aspects of care, such as complications that may have arisen from treatment. Collaboration among all clinical team members, the patient population, and government is central to good clinical management and efficient use of resources.

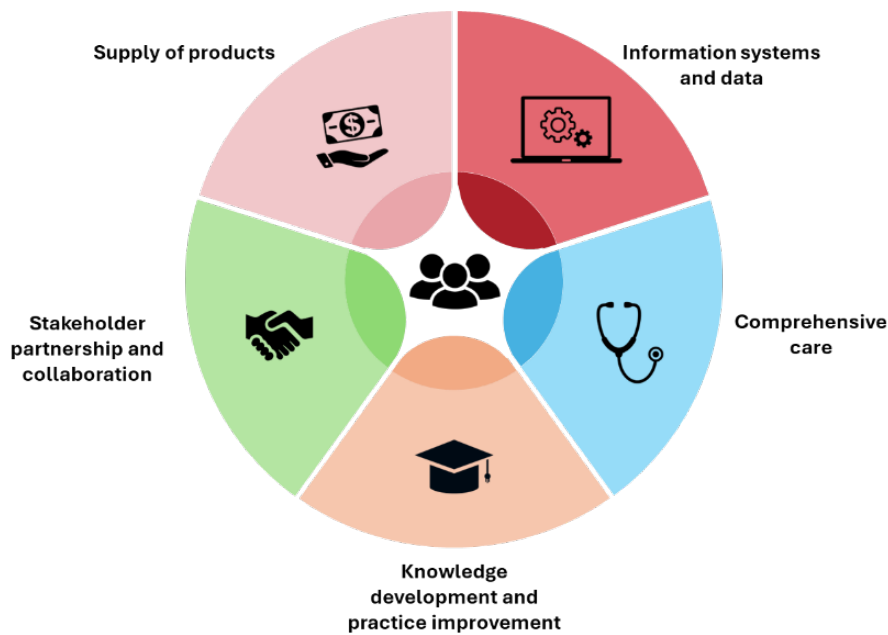
Australia has a well-established framework of policy, funding, health service and stakeholder arrangements for the care of people with bleeding disorders.

Within this framework, five key elements (shown in Figure 1 and discussed over the next pages) contribute towards the following complementary objectives:

- ensuring an appropriate and high-quality standard of care for people with bleeding disorders
- ensuring an effective and efficient use of products used in the treatment of people with bleeding disorders.

This framework should be read in conjunction with the World Federation of Hemophilia (WFH) Guidelines for the Management of Hemophilia, 3<sup>rd</sup> edition <sup>1</sup> and the Australian Haemophilia Centre Director's Organisation (AHCDO) Guidelines for the Management of Haemophilia in Australia Position Statement <sup>2</sup>.

**Figure 1 Key elements of the Australian framework for management of bleeding disorders**



## 2. Comprehensive care

Comprehensive care is a model of care that provides and coordinates hospital and outpatient care and associated services to people with bleeding disorders and their carers and families. The comprehensive care model seeks to ensure the coordinated management of all aspects of a bleeding disorder by a multidisciplinary team with specialised expertise.

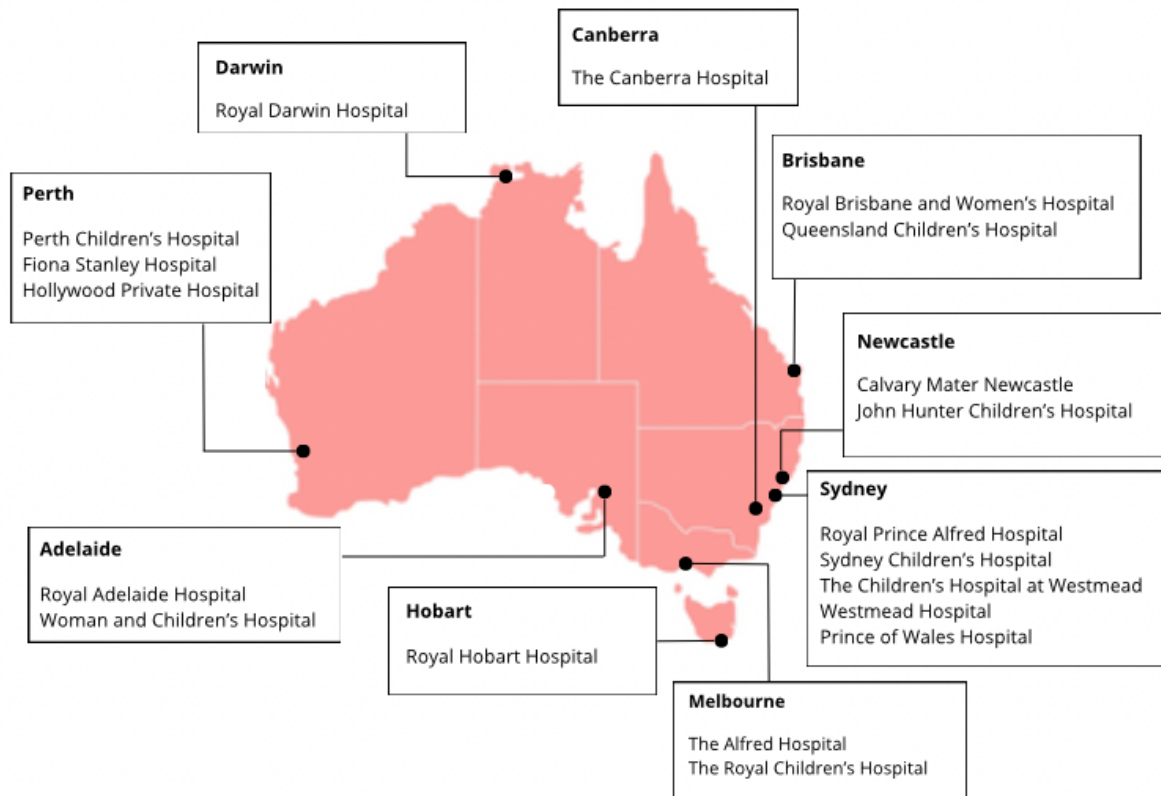
The benefits of comprehensive care include:

- reduced hospital days and treatment costs <sup>3</sup>
- reduced number of hospitalisation episodes, and decreases in school or work absences or unemployment <sup>4</sup>
- improved quality of life and reduced mortality <sup>5,6</sup>.

### Implementation of comprehensive care in Australia

In Australia, most people with bleeding disorders are managed clinically at Haemophilia Treatment Centres (HTCs) which are specialist centres that provide comprehensive care to people with haemophilia and other bleeding disorders. The comprehensive care model ensures that preventative and clinical management of the complex aspects of haemophilia and other bleeding disorders are given in a coordinated way by a multi-disciplinary team with specialised expertise within the one centre. HTCs were established following a decision by Australian Health Ministers Advisory Council (AHMAC) in 1998. The locations of the HTCs in Australia are shown in Figure 2.

**Figure 2 Location of Haemophilia Treatment Centres**



HTCs coordinate and, where possible, integrate patient care, research and education to provide the optimal use of expertise and resources within hospitals and the community. The model for HTCs varies between jurisdictions in relation to centralisation of services, size and age of patient population. HTCs maintain on-going dialogue with the client group in each state and territory. The role of State and Territory Governments is to designate 'HTCs' and negotiate the funding of the HTC including the purchase of therapeutic blood and recombinant products for distribution within states (or regions) and territories and provide equitable access.

HTCs should provide:

- a single point of care for patients with bleeding disorders with responsibility for the coordination, allocation and distribution of therapeutic resources for the treatment of patients
- a clinical service by experienced staff for patients with bleeding disorders and their families at short notice at any time of the day or night
- education and facilitation of treatment at home and in collaboration with other HTCs to ensure Australia wide care

- a counselling and advisory service for people with haemophilia and their families including genetic counselling and family planning
- specialist medical expertise related to haematology, surgery, rheumatology, infectious diseases and dental services
- specialist nurses and allied health services which includes physiotherapy, social work, psychology and podiatry
- a laboratory service able to carry out all investigations required for the accurate diagnosis of haemophilia and other inherited disorders of hemostasis and to have access, in association with other centres, to specialised testing facilities including genotyping
- records for all investigations, treatments, allocation of therapeutic products and adverse reactions, including data entry into the Australian Bleeding Disorders Registry (ABDR)
- a capability to participate in research including clinical trials
- educational programs and guidelines for medical staff, other personnel, patients and their families which promote care of patients with disorders of hemostasis
- an outreach service to isolated patients and treating medical services. The outreach service may include a haemophilia treatment facility located in a hospital that does not provide all the specialist services and a designated supervising medical practitioner
- data management for ABDR, to aid in capturing data critical to HTC staff for the day-to-day management of people with bleeding disorders and for supply management and policy purposes.

The implementation of the model for HTCs varies between states and territories in relation to resourcing, availability of a relevant range of medical and allied health services, centralisation and organisation of services, and demographics of the patient population.

Some care for people with bleeding disorders is managed by clinicians or health services that are not associated with a HTC. This may occur where a patient chooses to attend a private medical practitioner or health service, or where a bleeding disorder has not previously been identified and is initially diagnosed outside a HTC or becomes apparent as a complication of other medical treatment.

### 3. Treatments for bleeding disorders

There are several types of therapies used to treat bleeding disorders, with more in development. Treatment of bleeding disorders varies depending on the type of bleeding disorder and may include clotting factor replacement therapies, mimetics or other medicines including bypassing agents. Depending on several factors, treatment may be administered on demand to stop a bleeding episode or before surgery, medical or dental procedures, or may be administered as prophylaxis to prevent bleeding.

Some products used to treat people with bleeding disorders are funded by Australian governments through the National Blood Agreement (Agreement). The following section provides simplified information of the treatments for bleeding disorders, with a focus on products funded under the Agreement. For more comprehensive information, refer to the [WFH Guidelines for the Management of Hemophilia](#), 3<sup>rd</sup> edition <sup>1</sup> and the AHCDG Guidelines for the Management of Haemophilia in Australia [Position Statement](#) <sup>2</sup>.

#### Clotting factor products

A mainstay of contemporary medical care of people with bleeding disorders is the use of clotting factor concentrates. These products are infused to replace the specific blood plasma protein that is not present or functional at adequate levels in that individual. The aim is to achieve sufficient levels of that blood plasma protein to either avoid bleeding symptoms or to stop bleeding that has already occurred. Some clotting factor concentrates are funded by Australian governments under the Agreement to treat some patients with bleeding disorders (for specific indications see [Clotting factor and other products | National Blood Authority](#)).

Clotting factors can be derived from human blood plasma through the plasma fractionation manufacturing process. Some clotting factor products are also manufactured by commercial-scale expression from recombinant technology. Recombinant products can be standard half-life or extended half-life and are not made from human blood. Instead, they are made from genetically engineered cell lines. Standard half-life recombinant products have the same or similar half-life to plasma-derived clotting factors. Extended half-life recombinant products are modified to increase the duration of their effect. Although current plasma-derived clotting factors have an excellent safety record, recombinant products, where available, are often preferred by patients and clinicians due to the lower risk of transmission of diseases that are theoretically transmissible through human plasma.



Clotting factor products may be used to treat and manage bleeding disorders in several ways:

- ‘on-demand’ treatment for specific bleed events
- short-term prophylaxis to cover a specific surgery or other high-risk interventions or activities
- immune tolerisation therapy in cases where a patient has developed inhibitory antibodies to clotting factor therapy
- routine prophylaxis to maintain functional trough levels of clotting factor sufficient to prevent bleeding occurring.

### **Bypassing agents and mimetics**

Some people with bleeding disorders who are treated with clotting factor replacement therapy may develop ‘inhibitors’, which are antibodies that prevent the clotting factor from working properly. Bypassing agents are used to treat or prevent bleeds in people who have developed inhibitors and work because they contain other factors that can stimulate the formation of a clot and stop bleeding.

Another type of product, called ‘factor VIII mimetics’, are used to treat some patients with haemophilia A, with or without inhibitors. These products mimic the function of clotting factor VIII, allowing the blood to clot.

Some bypassing agents and mimetics are funded by Australian governments to treat some patients with bleeding disorders under the Agreement (see [Clotting factor and other products | National Blood Authority](#) for further information).

There are several other new treatments for bleeding disorders in development, including gene therapies and rebalancing agents.

### **Other products for treating bleeding disorders**

In addition to clotting factors, bypass agents and mimetics, other pharmaceutical products, medical devices and therapeutic interventions may be important for the care of people with bleeding disorders. They may be supplied and funded outside the national blood arrangements via hospital supply, or under the Pharmaceutical Benefits Scheme or Medicare Benefits Scheme. They include tranexamic acid, desmopressin, analgesia, antiviral therapy, immune modulating therapy, and mobility aids.

## 4. Supply under the national blood arrangements

Some clotting factor and other products including bypassing agents and factor VIII mimetics are supplied and funded in Australia through arrangements established under the Agreement. These arrangements provide an adequate, safe, secure and affordable supply of products to treat patients with bleeding disorders.

The National Blood Authority (NBA) conducts national tendering and contract negotiations for the supply of clotting factor products and other treatments which have been approved for funding under the Agreement. The NBA manages the national contracts and makes payment for products supplied. Funding is provided to the NBA for this purpose by the Commonwealth and state and territory governments through the cost sharing arrangements under the Agreement. Successive tendering and negotiation rounds conducted by the NBA since 2003 have provided a significant improvement in value for money for these products.

The national contracts managed by the NBA provide for supply of plasma-derived and recombinant clotting factors from both Australian and imported sources. Separate national contracts are in place for other products such as bypassing agents and mimetics. The NBA collaborates with the Australian Haemophilia Centre Directors' Organisation (AHCDO) and with state and territory representatives to undertake national supply planning, and to establish protocols for management of supply-risk scenarios that may eventuate. The Agreement also includes a process for evidence-based evaluation of proposals to add new or materially changed products into the national funding and supply arrangements.

In addition to a primary obligation to supply products to meet orders, national supply contracts include obligations for holding contingency supply reserves and other supplier obligations to ensure continuity of supply, as well as obligations to provide product support services and resources suitable for clinical personnel and (through a health-care provider) patients. Suppliers may also be required to provide services to support delivery of products direct to suitable patients, for home-based therapy under the supervision of a relevant HTC.

In determining the specific requirements and approach for a national tendering round, the NBA seeks input from a range of stakeholders which include clinicians, patient-groups, and industry stakeholders and obtains policy guidance from funding governments. These stakeholders are involved to provide expert or user input in the tender development and evaluation process.

For some products, the outcome of a tender process may involve a change in the specific brands of products supplied under the national arrangements, and the NBA cooperates closely with clinical and patient stakeholders and with suppliers in planning and supporting the transition process between products.

## Governance

In Australia, blood and blood related products and services are provided under the Agreement at no cost to patients. To ensure the supply of blood and blood related products and services is sustainable, governance arrangements for the supply of these products and services are in place. This is a collaborative effort between the Commonwealth and state and territory governments and is coordinated by the NBA.

Governance of blood and blood related products and services is not “one size fits all”, but will depend on several factors including clinical need, cost, and the risk of a product being supplied outside the agreed access criteria. Governance activities could range from monitoring the prescription and supply of products, reviewing access criteria to ensure they are in line with best clinical practice, or clinical or other review to ensure access to products is provided in line with the access criteria.

Apart from some exceptional circumstances, all products funded by the NBA under the Agreement are required to have Therapeutic Goods Administration (TGA) approval. Note, the approved funding for a product under the Agreement may not necessarily include all indications listed on the Australian Register of Therapeutic Goods for a specific product. There is a distinction between what indications the product has been evaluated as safe for use in Australia and the indications for which governments funding is most appropriate and will achieve value for money. To view which indications are funded for each product under the Agreement [visit Clotting factor and other products | National Blood Authority](#).

## 5. Stakeholder partnership and collaboration

The effective treatment and care of patients with bleeding disorders in Australia benefits from the involvement of several important government, clinical, and patient stakeholder groups. These groups have various individual roles and responsibilities while collaborating to ensure effective patient care.

### Roles and responsibilities

Some of the organisations that contribute to the care of patients with bleeding disorders in Australia include:

- **National Blood Authority (NBA):** the NBA manages and coordinates arrangements for the supply of blood and blood related products and services in Australia. Under the national blood arrangements, part of its role is to deliver an uninterrupted supply of blood and blood related products and services to people with bleeding disorders in Australia.
- **Australian Haemophilia Centre Directors' Organisation (AHCDO):** AHCDO is the national medical body for bleeding disorders in Australia. With support from the NBA, AHCDO provides a range of advice, services and management activities to support the effective management of bleeding disorders in Australia.
- **Haemophilia Foundation Australia (HFA):** HFA and state and territory local foundations represent the Australian community of people with bleeding disorders and their carers and families. HFA is committed to improving treatment and care through representation and advocacy, education and the promotion of research. The NBA provides support to HFA for its secretariat, agreed education activities and policy advice.
- **Specialist Health Professional Groups:** several specialist health professional groups, supported by HFA, assist in the comprehensive care of people with bleeding disorders by providing expertise in several disciplines. These groups include:
  - **Australian Haemophilia Nurses Group**
  - **Australia and New Zealand Haemophilia Psychosocial Group**
  - **Australian and New Zealand Physiotherapy Haemophilia Group**
- **Australian Bleeding Disorders Registry (ABDR) Data Managers' Group:** This group receives support from the NBA through AHCDO and is responsible for entry of data into the ABDR.

## Partnership and collaboration

The stakeholders described above collaborate through formal partnerships or informal processes to oversee or provide input into key outcomes, or to undertake projects to support or improve care for people with bleeding disorders. Some key examples include:

- Management of patients through the AHCDO Clinical Advisory Committee (CAC), including peer review and clinical advice to clinicians managing complex patients.
- Regular education meetings around topics on bleeding disorders.
- Informing procurement processes and associated consultation, reference group or transition committees that oversee major national procurement actions for clotting factors. Australia's national procurement arrangements realise the best product price and associated service arrangements available globally. This price increases affordability, and hence provision of effective bleeding disorders care <sup>7</sup>. The expertise and involvement of key clinical and patient stakeholder groups in these processes is of great value in achieving these outcomes.
- Clinical and stakeholder reference groups that oversee the development of supporting clinical guidelines. These clinical guidelines record an increasing level of national consensus on significant aspects of the care and management of bleeding disorders, and the key indicators to be used to guide future quality improvement.
- Updates to ABDR, MyABDR and associated governance frameworks.

## 6. Information systems and data

### Australian Bleeding Disorders Registry

The Australian Bleeding Disorders Registry (ABDR) is a database developed as a collaborative project by the NBA, AHCDO and HFA on behalf of Australian governments and managed by the NBA. The ABDR collects clinical information related to the treatment of people with bleeding disorders, including information about patient diagnosis, treatment details, hospital admissions and administrative information, and details on ordering, supply and use of products to treat bleeding disorders. Information is entered into the ABDR web-enabled software by staff at HTC's. Patients with a bleeding disorder should be registered on the ABDR, and their product use recorded.

The ABDR provides the following benefits:

- a single point of access to all relevant individual clinical data relating to the management of bleeding disorders for clinicians treating these patients
- exchange of selected information between states and HTC's as appropriate
- national demographic information (e.g. age and sex) of people with bleeding disorders
- national data on inhibitor incidence and outcomes of treatment
- allied health (physiotherapy and psychosocial) interactions and outcomes
- recording of product usage, which provides governments with information on product requirements to inform supply and funding planning to meet the needs of Australians with bleeding disorders
- other relevant health information

The ABDR provides health-care teams and support staff with a record that enables them to monitor and manage treatment over time to improve patients' quality of life.

The ABDR is managed on a day-to-day basis by the NBA in accordance with the guidance and policy provided in the NBA Data Governance Framework ([NBA Data and Information Governance Framework | National Blood Authority](#)). Patient privacy and confidentiality are paramount to this framework, and individual patients are required to give consent for their data to be recorded in the ABDR. In addition, stringent security protocols are embedded into the technical architecture of the ABDR. These effectively control access to personal data, ensuring that this information is only accessible to treating health professionals and authorised support staff.

On application to the NBA, de-identified information from the ABDR may be used for research purposes by authorised organisations or individuals, to understand and improve treatment for bleeding disorders. Considerations for the release of any information for research or other purposes not related to the clinical treatment of individual patients are made under the governance arrangements described in the NBA Data Governance Framework. The NBA must be satisfied that the public interest in the research activity outweighs to a substantial degree the public interest in privacy. To ensure this, ethics considerations must be applied in accordance with The National Statement on Ethical Conduct in Human Research (2023), which sets out the values and principles that apply to all human research.

For comprehensive information on the ABDR, refer to the NBA website [Australian Bleeding Disorders Registry | National Blood Authority](#).

### MyABDR

MyABDR is a secure app for use on smart devices or home computers, developed as a collaborative project by the NBA, AHCDO and HFA on behalf of Australian governments, for use by people with bleeding disorders or their parents or carers. There is also an alternative print-based MyABDR treatment diary. MyABDR is the preferred method to record home treatments for both prophylaxis or bleeding episodes, and to manage treatment product stock. The MyABDR app and website link directly to the ABDR so that data entered are available to the patient's treating clinician. By enhancing the accurate recording of bleed frequency and product usage, and making that information accessible to the clinician, MyABDR aids decision-making regarding treatment regimens and optimises patient care.

### Data reporting

Health professionals can use the relevant data recorded in ABDR for the care and treatment of individual patients, and HTCs can use relevant data recorded in ABDR in managing the provision of comprehensive care services for those patients under their HTC.

Several useful national level reports are produced from de-identified data in ABDR, including:

- annual reporting, including published reports which provide an overview of how many patients have bleeding disorders and the products they have received
- benchmarking data is available to individual centres to identify variation in management among centres, and to help identify areas in which differences can be examined, to assist in standardising practice

- Australian Haemophilia Safety Surveillance System (AUSHASS) scheme which reports adverse event reporting and recording to AHCD0 and the AHCD0 CAC
- national contributions to the World Federation of Hemophilia Annual Global survey.

Individual HTC's, and the AHCD0 and ABDR Research Fellows are also able to submit data requests for summary data regarding their patient population, to enhance clinical management. The NBA's Data Governance Framework outlines the overall management of the availability, usability, integrity, and security of data.

## 7. Knowledge development and practice improvement

Elements of the national framework for management of bleeding disorders in Australia enable and support a range of activities that seek to evaluate, maintain and improve an appropriate and high-quality standard of patient treatment care, and the effective and efficient use of products to treat bleeding disorders. These elements also include activities related to knowledge development and practice improvement, some of which are summarised below:

- **Education and training** – the NBA, patient advocacy groups and specialised health professional groups (including HFA and AHCD0) are regularly involved in educational activities. These include registrar training events, the annual AHCD0 education day, HFA Australian bleeding disorders conference and participation in other national and international conferences/workshops.
- **Promoting health and awareness** – AHCD0, HFA and other stakeholders increase awareness and promote health in relation to bleeding disorders in Australia through promulgation of information, and awareness and health promotion campaigns including Bleeding Disorders Awareness Month. Members of AHCD0 and other specialist health professional groups also contribute to patient education materials in partnership with HFA.
- **Practice benchmarking, development and peer review** – forums for peer discussions of difficult clinical management decisions are provided by the AHCD0 CAC. In addition, the provision of regular benchmarking data by the NBA and AHCD0 to individual centres will enable the examination of variation in practice and aid in the standardisation of management where appropriate.
- **Guidelines, consensus and position statements** – the NBA, AHCD0, HFA and other stakeholders keep abreast of international guidelines and are committed to the development of clinical guidelines and position statements to provide guidance for the management of patients with bleeding disorders.



- **Research and publications** – on application, and in accordance with ABDR terms and conditions and privacy arrangements, the NBA can provide ABDR data to AHCD, HFA, universities, pharmaceutical companies, healthcare professionals, government agencies and other interested stakeholders for use in research, publications and other purposes not related to clinical treatment of individual patients. Ethics approval for use of ABDR data is a key component of examining national data to help answer key research questions.
- **Continuous improvement** – the NBA is committed to continuous improvement in practice and governance in line with emerging evidence, and communication with stakeholders. Stakeholder feedback on this framework will be taken into consideration to ensure accuracy and good governance.

## Appendix A – Important links

Topic	Hyperlink	Web address
Link to the NBA website home page	<a href="#">Home   National Blood Authority</a>	https://www.blood.gov.au/
Link to the National Blood Agreement	<a href="#">National Blood Agreement   National Blood Authority</a>	https://www.blood.gov.au/national-blood-agreement
Information on clotting factor and other products used to treat people with bleeding disorders that are funded by the NBA.	<a href="#">Clotting factor and other products   National Blood Authority</a>	https://www.blood.gov.au/blood-products/clotting-factor-and-other-products
Link to the NBA's Data Information and Governance Framework.	<a href="#">NBA Data and Information Governance Framework   National Blood Authority</a>	https://www.blood.gov.au/nba-data-and-information-governance-framework
Link to the information about the ABDR on the NBA website.	<a href="#">Australian Bleeding Disorders Registry   National Blood Authority</a>	https://www.blood.gov.au/clinical-guidance/bleeding-disorders/australian-bleeding-disorders-registry
Link to the AHCDO website.	<a href="#">Australian Haemophilia Centre Directors' Organisation</a>	https://www.ahcdo.org.au/
Link to the HFA website.	<a href="#">Haemophilia Foundation Australia - Representing the Australian bleeding disorders community</a>	https://www.haemophilia.org.au/

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